

Angst voor terugkeer van kanker

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Disclosure belangen

(potentiële) belangenverstrengeling	Geen
Voor bijeenkomst mogelijk relevante relaties met bedrijven	Geen
<ul style="list-style-type: none">• Sponsoring of onderzoeksgeld• Honorarium of andere (financiële) vergoeding• Aandeelhouder• Andere relatie, namelijk ...	<ul style="list-style-type: none">• geen• geen• geen• geen

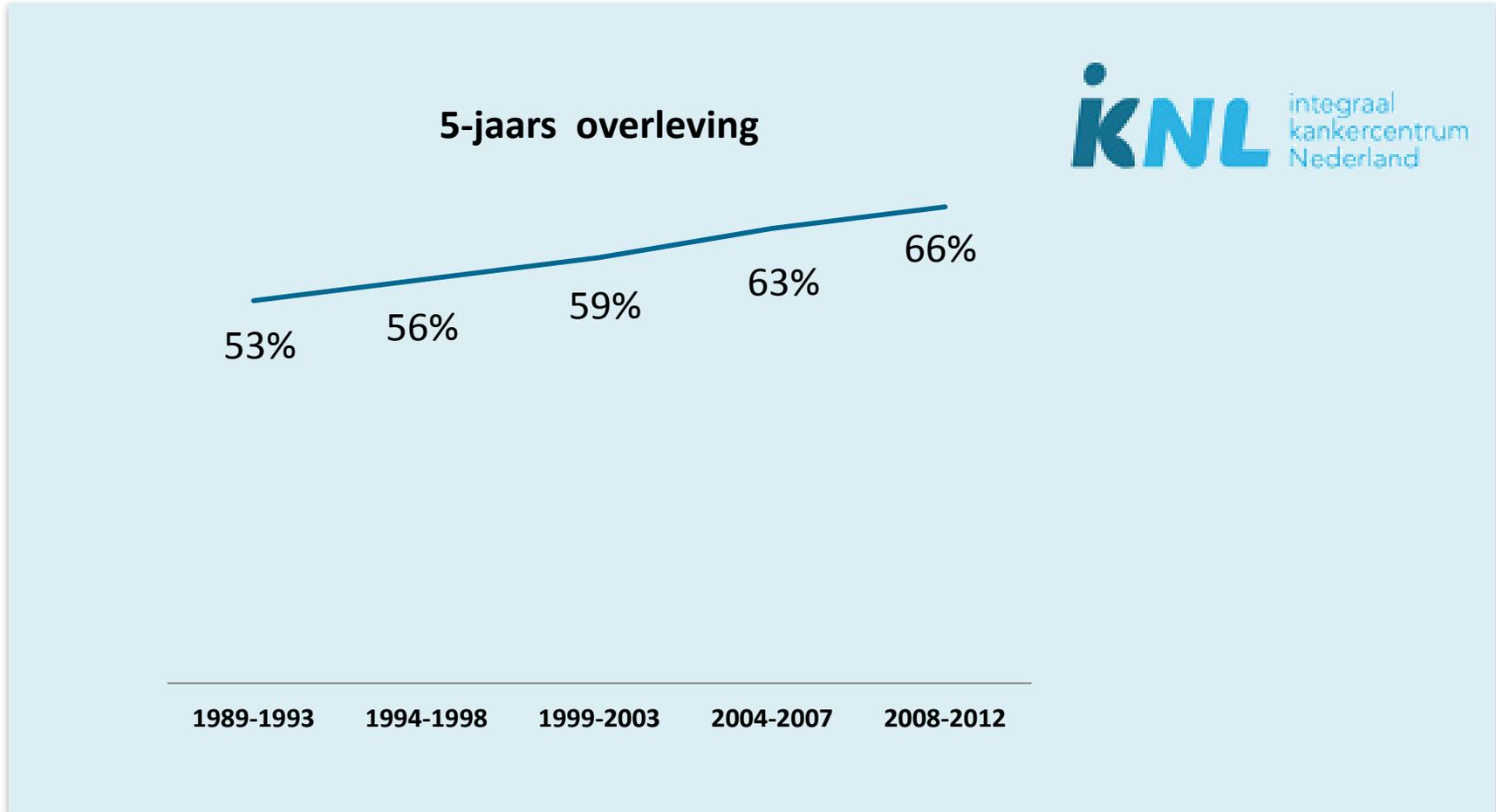
Het zwaard van Damocles



“Fear, worry, or concern relating to the possibility that cancer will come back or progress”

- Normale emotionele reactie bij kanker
- Minder vertrouwen in eigen lichaam
- Hoge angst heeft negatieve invloed op welbevinden
- In de top 5 van onvervulde zorgbehoeften

Verder leven met kanker in Nederland 1989-2012





De angst voor kanker beheerste mijn leven

*Mevrouw Groenen:
"Ook toen ik genezen was
verklaard, beheerste de
kanker mijn leven"*

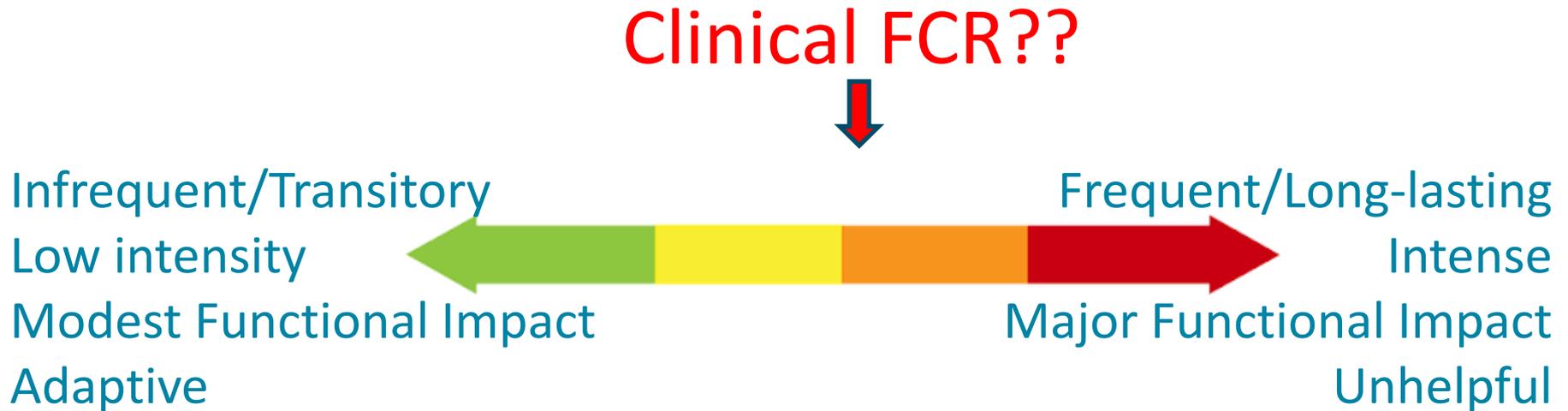
Op ieder ziektebeeld, iedere behandelmethode en iedere innovatie heeft iedereen uiteraard zijn eigen perspectief. In deze rubriek brengen we perspectieven bij elkaar. Dit keer het perspectief van een patiënt na een behandeling voor kanker. Dat deze een zekere angst houdt is logisch en zelfs functioneel. Maar angst kan ook de overhand nemen en het leven van de (ex-)patiënt gaan bepalen. Dat gebeurde bij mevrouw Groenen. De afdeling Medische Psychologie van het Radboudumc ontwikkelde voor haar en haar lotgenoten een protocol voor een psychologische behandeling waarmee de angst tot reële proporties kan worden teruggebracht. Ook dat perspectief zien we in dit artikel met psycholoog Petra Servaes én de ex-patiënt.

Characteristics of FCR

- Chronic worry & rumination
- Intrusive thoughts or images
- Excessive bodily-checking & reassurance seeking; AND/OR
- Avoidance of cancer reminders
- Limited ability to plan for future



Spectrum of FCR



FORwardS: International Expert Special Interest Group on FCR



- Founded August, 2015, University of Ottawa Consensus Meeting
- Over 30 members (Researchers, Clinicians, Consumer)
- Chairs: Belinda Thewes (Radboudumc)
Gozde Ozakinci (University of St Andrews, Scotland)
- Aims:
 - Stimulate research on FCR;
 - Facilitate international collaboration; and
 - Promote educational activities on FCR





FORwardS: International
Expert Special Interest
Group on FCR



Ottawa, augustus 2015

How prevalent is FCR?

- From 46 studies reporting prevalence rates on average:

“Some” FCR	“Moderate” FCR	“High” FCR
Mean (Range)	Mean (Range)	Mean (Range)
73% (39-97%)	49% (22-87%)	7% (0-15%)

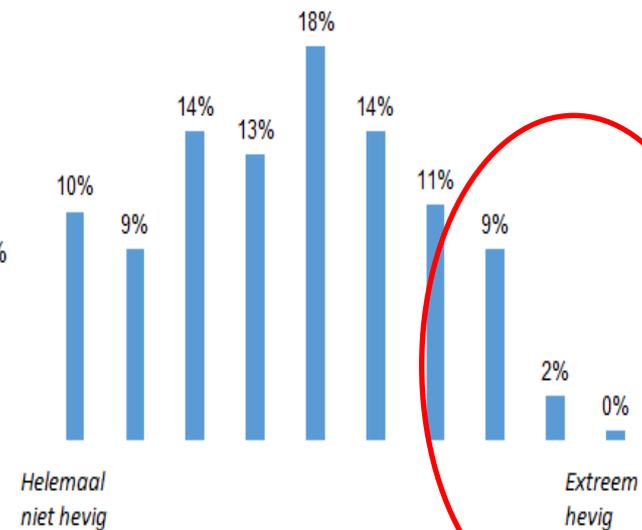
- Multiplicity of outcome measures
- Sample characteristics
- Lack of consensus definition for “High” or “Clinical” FCR

Borstkanker

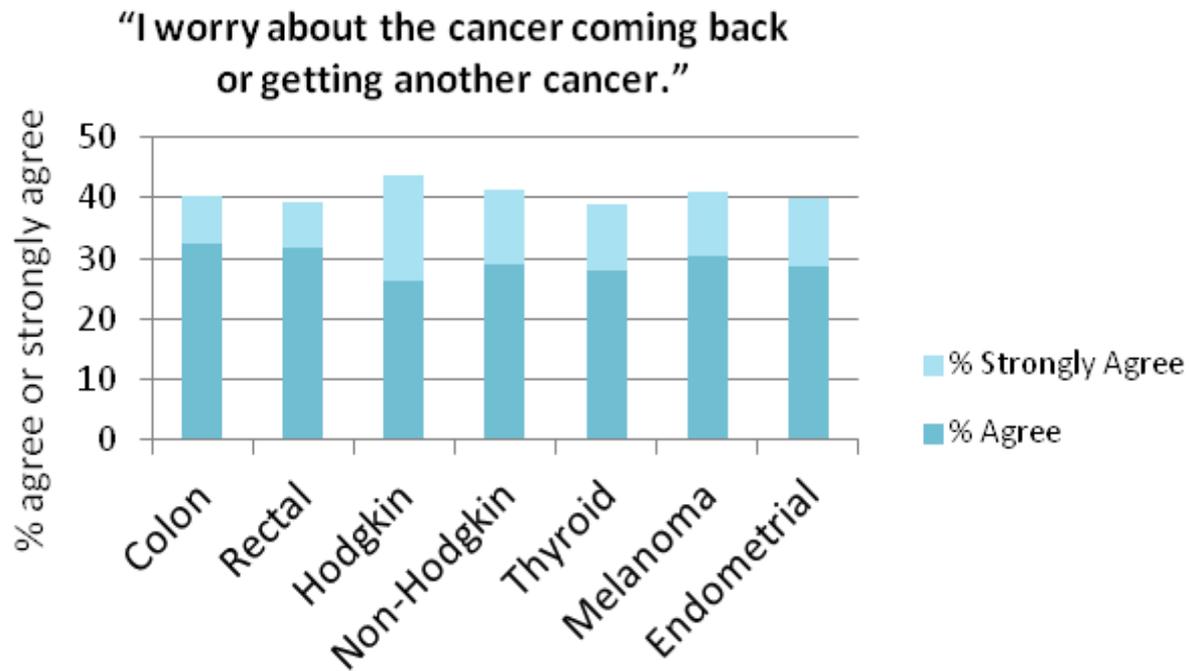
Ervaar jij angst voor terugkeer van borstkanker /
uitzaaiingen (gemiddeld genomen)? (n=948)



Hevigheid angst (n=932)



2615 cancer survivors stage I or II disease



Hogere angst

- Jongere leeftijd
- Vrouwen
- Korter na diagnose
- Gevorderde ziekte

Cancer Worry Scale

Author	Cancer type	Stage	N	High FCR % (CWS)
Custers et al. 2014	Breast	I-III	194	31%
Custers et al. 2015	Colorectal	I-III	76	38%
Van de Wal, 2016	Prostate	Localised	283	36%
Custers et al, 2015	Sarcoma (GIST)	Localised Metastatic	54	52%
Thewes et al. in preparation	diverse AYA	curative intent	73	62%

Prevalence

A subset of individuals continue to have high FCR long-term despite good prognoses.

Examples:

- German registry study: 2671 Breast Ca. survivors (mean 8 years post-diagnosis) found 17% mod-high FCR
- EORTC Clinical trials: 1336 Testicular Ca Survivors (mean 11.5 years post-diagnosis) found 24% worry '*quite a bit*' and 7% '*very much*' about FCR during the past week

Prevalence: Unmet need

- FCR is consistently in the top 5 unmet needs for help amongst survivors

Author /Year	Country	Sample size	Cancer Type	% with unmet Need for help with FCR	Rank of Need
Armes et al. 2009	UK	1152	Mixed	26-30%	1
Boyes et al. 2012	Australia	1323	Mixed	14%	2
Willems et al. 2015	NL	215	Mixed	23%	4

Who develops FCR?

Consistent evidence:

- Younger age
- Symptom burden (Pain, Fatigue, Body Image Concerns)



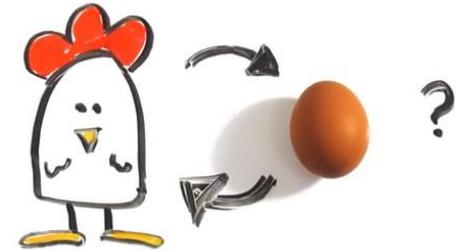
Inconsistent evidence:

- Female Gender
- Lower Education
- Prognostic factors (TNM, PSA, +ve Margins)
- Having chemotherapy
- Personality factors (e.g. Optimism, Neuroticism)
- Limited social support
- Minority group ethnicity
- Lower Income
- Having children
- Physical comorbidity

Psychological Factors Associated with FCR

Moderate and significant associations between FCR and

- Depression
- Anxiety
- Distress
- Intrusive thoughts
- Illness beliefs
- Beliefs about role cognition (meta-cognitions)



BUT most data is cross-sectional, more prospective research is needed!

Comorbidity

Some overlap between clinical FCR and anxiety disorders (GAD, health anxiety, PTSD) (10-40%) but **most survivors with high FCR** have no co-morbid psychological disorder

Ref: Thewes et al. Psychooncology. 2013 ;22(12):2797-806;

Dinkel et al. Gen Hosp Psychiatry, 2014

Simard, Thewes et al. 2013 Cancer Surviv. 2013 Sep;7(3):300-22.

Roth et al. Psychosomatics 2006;47(4):340-7.

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FCR does not necessarily decrease with time

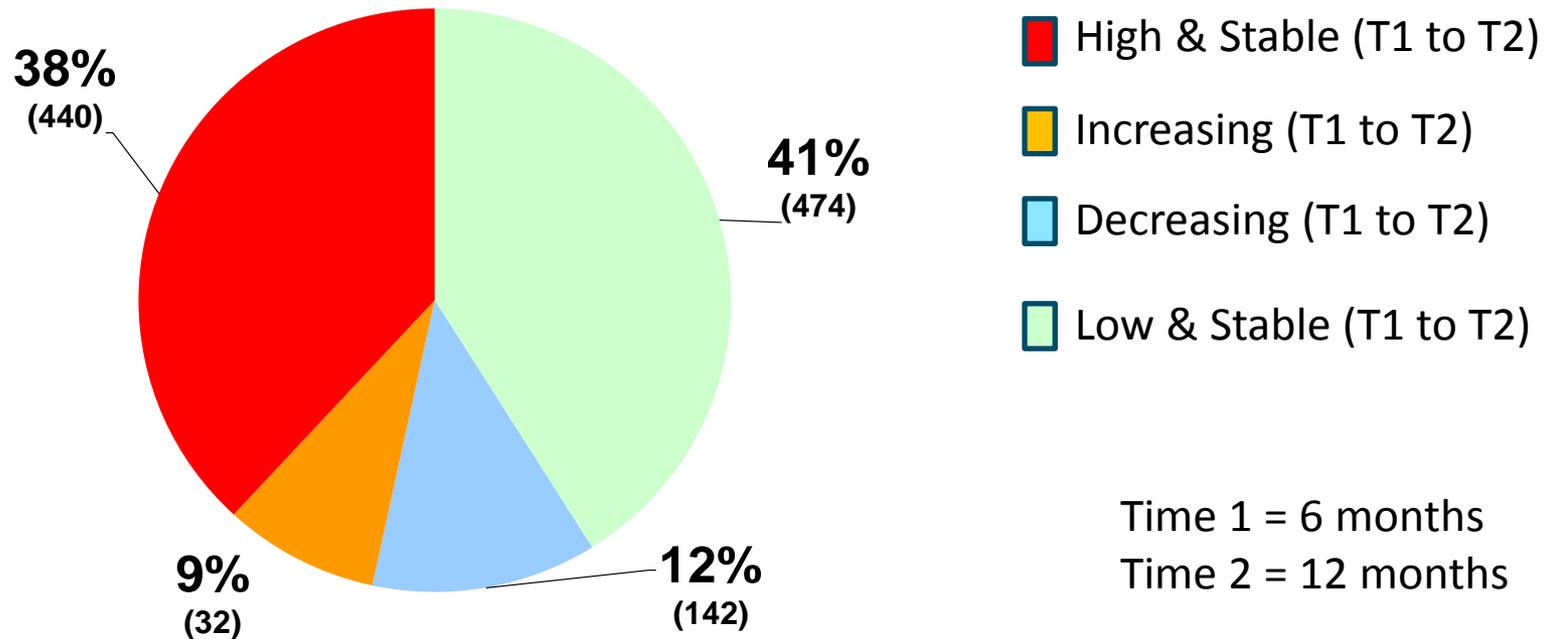
Systematic Review: 22 longitudinal studies (f/up 3 months – 6 years)

- 18 studies = STABLE or initial decrease then STABLE
- 2 studies= INCREASES
- 2 studies= DECREASES



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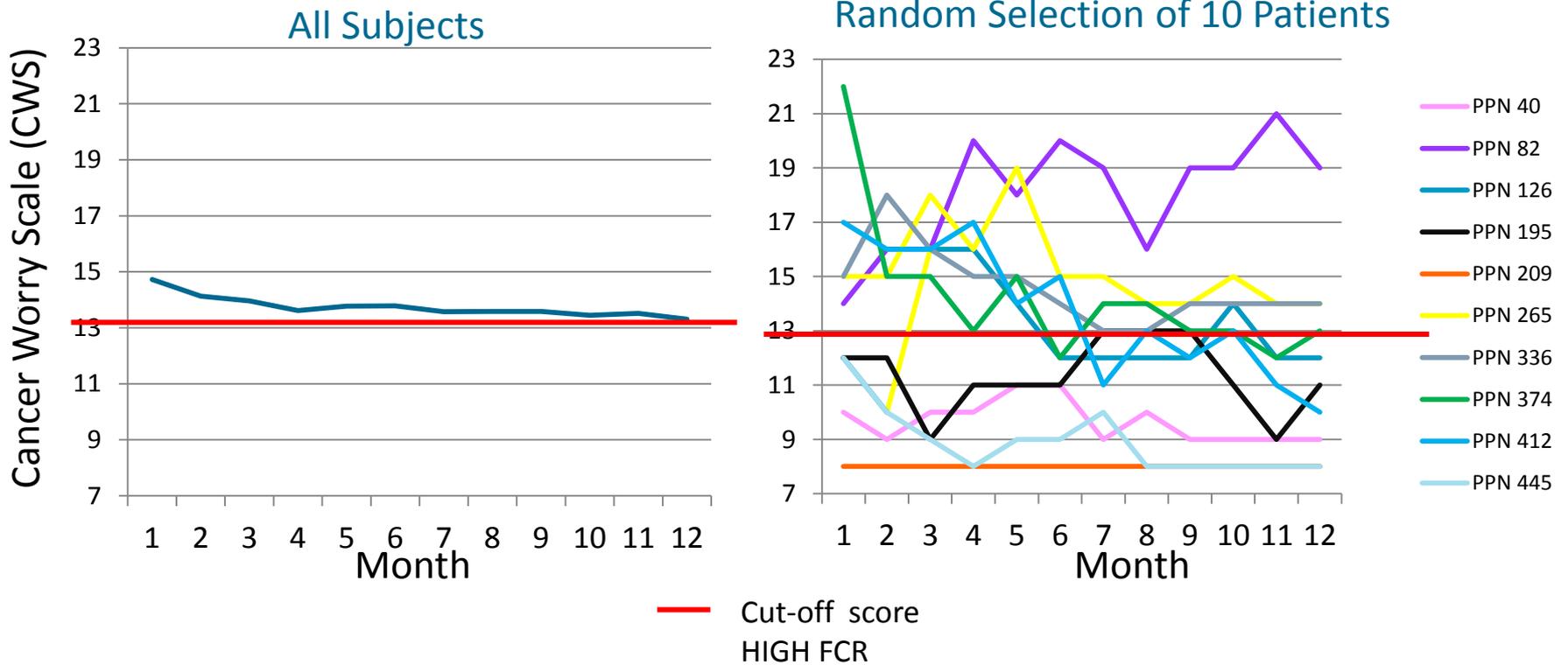
NSW Cancer Survivors Study (n=1154)

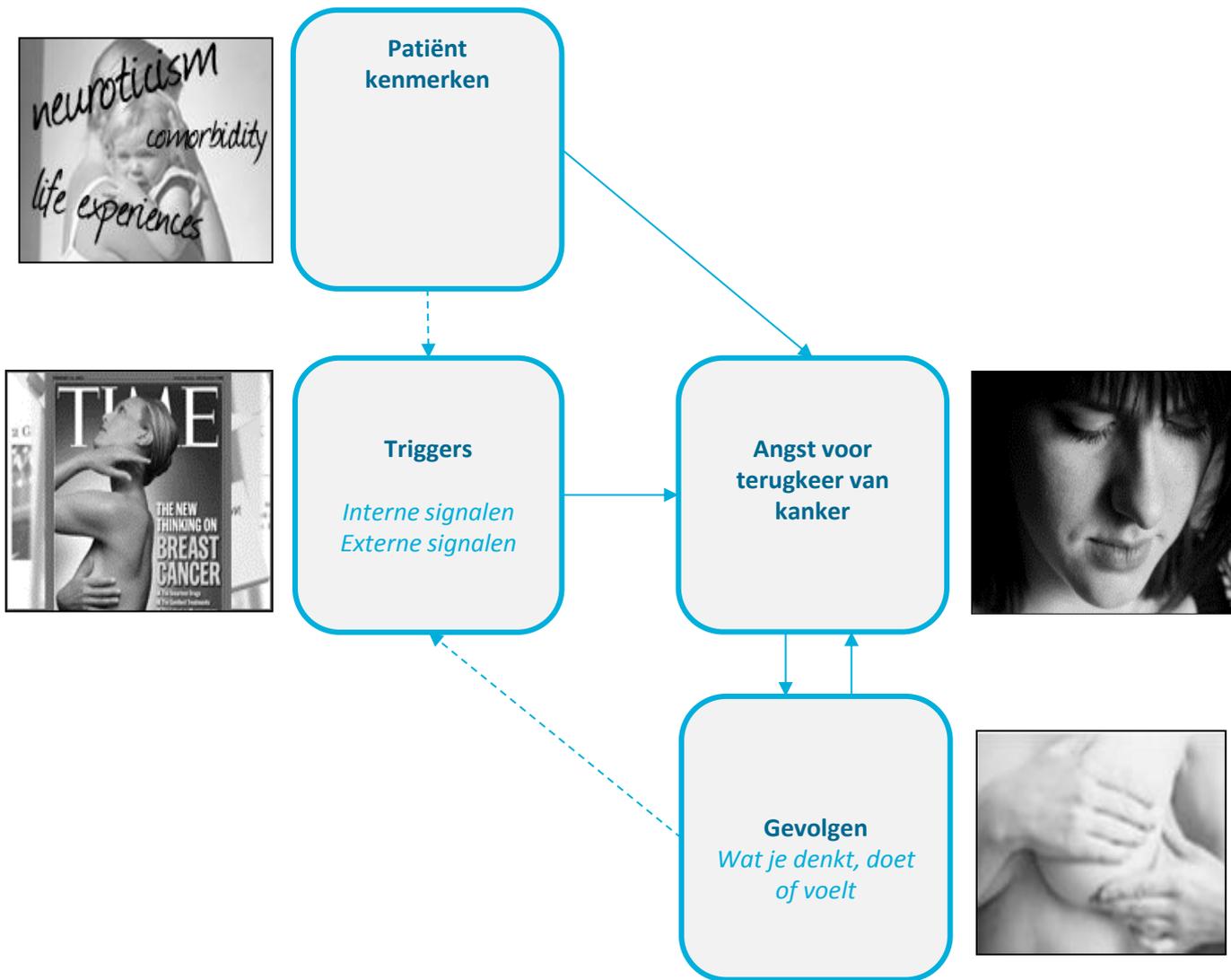


“Worry about the cancer returning or getting worse” (Mini-MAC)

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Trajectories of FCR in Dutch Breast Cancer Survivors 0-5 yrs after Primary Treatment (n=462)





Triggers

Trajectories not well understood- considerable individual variability

Known triggers: Somatic symptoms
 Cancer reminders
 Medical tests & follow-up visits



Healthcare Costs

Some evidence to show those with high FCR:

- reluctant to be discharged from specialist care
- more unscheduled medical appointments
- more visits to emergency department
- spend more on complementary therapies

Interventions for FCR



Fear of Progression Intervention

Technical University
Munich, Germany



FORT STUDY

University of Ottawa,
Ottawa, Canada



ConquerFear

Sydney University,
Sydney, Australia



Radboudumc,
Nijmegen, NL



Mini-AFTER

University of St. Andrews,
St Andrews, Scotland

ernstige
problemen
10%

enige
problemen
20%

normale
emotionle
reactie
70%

psycholoog

coach

arts en
verpleegkundige

psychotherapie

counseling

psychosociale
zorg

Persoonsgerichte zorg

Medische Psychologie

Instellingen voor psychosociale oncologie

Oncologische revalidatie

Verpleegkundige zorg, huisarts

Zelfhulp op internet

Inventariseren: hoe ernstig, welke risicofactoren?

Blended therapy for FCR



Blended Therapy

- a combination of online and face-to-face therapy*

SWORD: blended cognitive behavioral therapy (bCBT) to manage FCR in cancer survivors

Face-to-face (F2F) sessions

E-consultations

Online psycho-education



Opdracht	Status
0.1 LUISTEREN: Voord van welkom. Aangenaam met u kennis te maken.	✓
0.2 LEZEN: Angst voor terugkeer van kanker.	✓
0.3 LEZEN: Wat kan ik de komende 3 maanden verwachten?	✓

Blended CBT for FCR

5 individual F2F sessions (1 hour) + 3 e-consultations (15 min) in 12 weeks

F2F sessions delivered by two experienced, trained, supervised psychologists

Key components

- Psycho-education
- Cognitive restructuring
- Behavioral modification
- Mindfulness/relaxation

Website: information, assignments, video's, tests

- *Reading, Doing, Listening, Testing*

SWORD: a randomized controlled trial

- Breast, prostate and colorectal cancer survivors.
 - 6 months - 5 years post primary treatment (curative intent)
 - high levels of FCR (Cancer Worry Scale ≥ 14)
- Intervention group: bCBT
Control group: care as usual (CAU)
- Patient recruitment: Jan 2014 – Jan 2016
- Primary outcome: FCR severity (Cancer Worry Scale)

Radboudumc

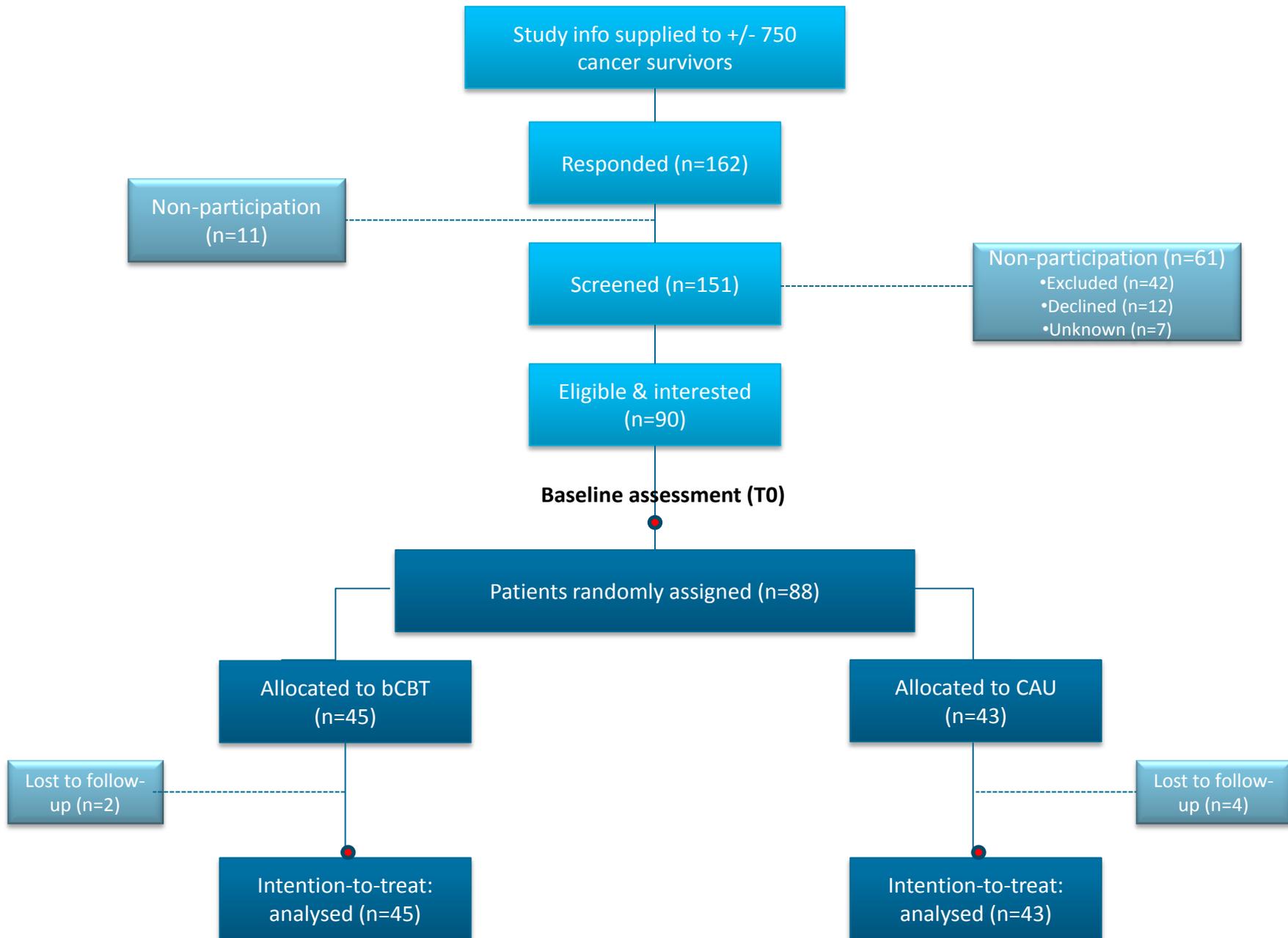

Canisius-Wilhelmina Ziekenhuis

maasziekenhuis
Pant&in


bernhoven

Ziekenhuis
Gelderse
Vallei


SWORD: Flowchart



Patient characteristics

Total sample:

- 53% female
- Mean 58.9 years (range 31-77)
- Cancer site: breast 41%, prostate 34%, colorectal 25%
- Time since diagnosis: 2.6 years (0.6 to 5.9)

No significant difference between groups prior to intervention on:

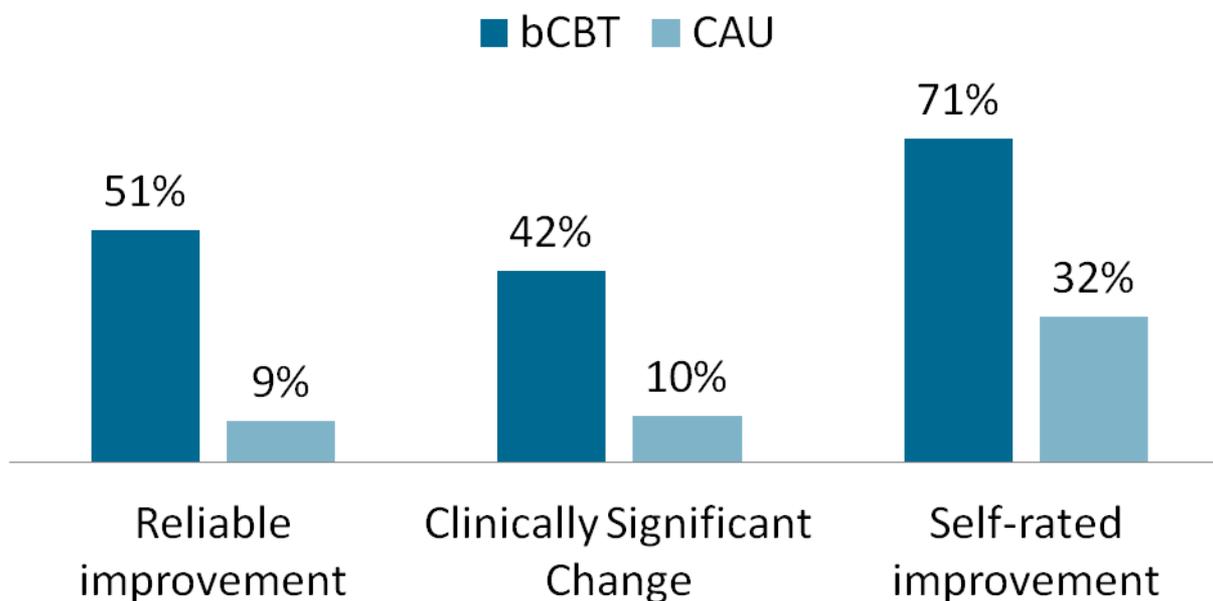
- Baseline FCR
- Clinical and demographic characteristics
 - Age / Gender / Education / Marital status
 - Cancer type / Treatments received / Time since diagnosis

SWORD: intervention

- 66% (n=28) bCBT starters completed all 8 sessions
4 patients could not complete therapy due to sick leave of one therapist
- Patient reasons for discontinuing:
 - FCR reduction established
 - Medical/mental health comorbidity
 - bCBT not meeting expectations
 - Other need-for-help question
 - Unease caused by bCBT
 - Unknown / no-show
- Mean duration of therapy was 10.9 weeks (range 0 – 28)
- Integrity check, 5% sessions audiotaped by 3 independent raters
 - 93%** of the time spent in therapy was relevant for bCBT
 - 75%** of sessions covered all required session components

SWORD effect

Effect	Mean (SD/SE)		Mean diff. (95% CI)	p	Effect size (Cohen's d)
	bCBT (n=45)	CAU (n=43)			
<i>Fear of recurrence (CWS, range 8-32)</i>					
T0	19.6 (3.7)	19.6 (3.7)	0.086 (-1.647 to 1.573)	0.914	0.76
T1 (adjusted)	15.1 (0.4)	18.6 (0.1)	-3.459 (-4.663 to -2.255)	<0.001	



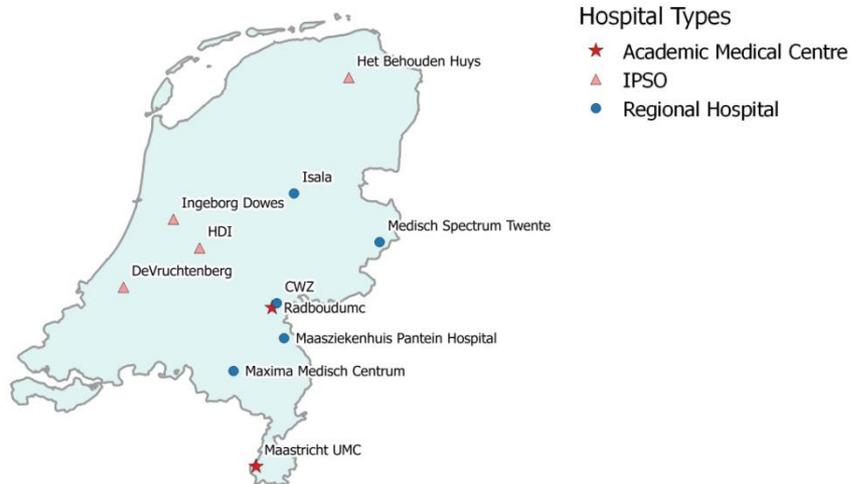
SWORD: website use

- 84% used the website; 16% felt they lacked the required computer skills
- all non-users were male and 90% diagnosed with prostate cancer

	All website users (n=35) Median (range)	Completers only (n=25) Median (range)
Number of website logins during therapy	12.0 (1 – 29)	13.5 (5 – 29)
Inlog duration per session (minutes)	28.3 (3 – 64)	30.0 (8 – 64)
Number of assignments opened	52.0 (0 – 54)	54.0 (33 – 54)
Number of assignments submitted	47.0 (0 - 54)	51.0 (27 – 54)

SWORD-NL Implementatie

- 4 instellingen voor psychosociale oncologie
- 8 afdelingen medische psychologie in ziekenhuizen



Take home messages

- Angst voor terugkeer van kanker varieert van normale reactie tot ernstig invaliderend probleem
- In de Top 5 onvervulde zorgbehoeften van patiënten met kanker
- Gevalideerd screeningsinstrument beschikbaar (Cancer Worry Scale)
- Evidence based cognitieve gedragstherapie, face-to-face en blended

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Patient recruitment

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